## Analysis of Population and Services For Visually Impaired Persons in Wisconsin

# Bureau for the Blind Division of Disability and Elder Services Department of Health and Family Services State of Wisconsin September 2003

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#### **Introduction**

The Bureau for the Blind - "Bureau", Division of Disability and Elder Services, Wisconsin Department of Health and Family Services, provides rehabilitation services at no cost to individuals who are blind or visually impaired. The Bureau typically provides independent living services for older adults in their homes, in some cases providing magnification or other assistive devices. The Bureau also works with clients receiving vocational rehabilitation. During calendar year 2002, the Bureau served nearly 2,100 visually impaired clients, the average age of whom was 79 years old.

National studies have shown that about 2 percent of the general population has a visual impairment severe enough to prevent reading normal newsprint even with corrective lenses<sup>1</sup>. Among people over the age of 75, this level of visual impairment occurs at a much higher rate, affecting nearly 1 in 4 individuals. In Wisconsin, the Bureau estimates that as many as 200,000 residents are blind or visually impaired, and many more are believed to have eye conditions that may potentially result in permanent vision loss.

A recent client survey conducted by the Bureau clients indicated that macular degeneration, diabetic retinopathy, glaucoma, retinitis pigmentosa, and optic atrophy comprised 87 percent of the eye diseases they experienced. To evaluate the magnitude of this problem, the Bureau and the Wisconsin Academy of Ophthalmology conducted an additional survey of ophthalmologists in 2001-2002 to determine the frequency with which they encounter these five eye diseases in their practices.

Approximately 37 percent of those practicing in the state, or 52 ophthalmologists, participated in the study. Over a three-week survey period, these physicians reported seeing 1,340 patients from 59 counties who had eye diseases that can lead to legal blindness. If the responding ophthalmologists are representative of ophthalmologic services in Wisconsin, then between 2,600-4,000 individuals with potentially blinding eye diseases are examined in the state every week.

In addition, recent national research<sup>2</sup> has indicated that older blind or visually <sup>1</sup>impaired people are two to three times more likely than their sighted peers to have

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<sup>&</sup>lt;sup>1</sup>Leonard, R. 1999. *Statistics on Vision Impairment: A Resource Manual*. New York: Lighthouse International.

difficulty walking, getting in or out of chairs or beds, be injured in falls, have heart disease, hypertension, or strokes, and have problems managing their medications. In contrast, however, a Bureau consumer survey conducted in 2001 indicated that 81 percent of clients were less dependent on others after receiving services from the Bureau; 80 percent had improved their ability to read; and 69 percent said they were in better control of managing decisions important in their lives.

Although it is clear that the Bureau is significantly helping many older, visually impaired residents of Wisconsin, due to limited availability of funds the Bureau is still able to serve only about 1 percent of the population, far less than the current estimates of the individuals reportedly in need of services. Meanwhile, every measure of demographics points to a rapidly growing at risk population. Evidence also suggests that minority populations are being underserved, as they were rarely reported among the clients served in the Bureau ophthalmologist survey. Additional data are necessary to develop a more effective model for client services, establish adequate staffing and equipment needs, and project budgetary requirements.

For additional information on the Bureau for the Blind, please call us toll free at 1-888-879-0017. You may also access information on our Web page at www.dhfs.wi.state.us/blind.

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<sup>&</sup>lt;sup>2</sup> Crews, J., 2000. Aging and vision loss: A conceptual framework for policy and Practice, and Orr, A., 2000. The knowledge base for collaboration between the fields of aging and vision loss. Both in Crews, J. and F.Whittington (eds)., *Vision Loss in an Aging Society*. American Foundation For the Blind Press, New York.

<sup>&</sup>lt;sup>3</sup> Conducted survey of Wisconsin Academy of Ophthalmology to determine encounter rate of five most prevalent eye diseases in Wisconsin.

<sup>&</sup>lt;sup>4</sup> Analyzed Wisconsin Academy of Ophthalmology survey data.

### <u>Incidence and Prevalence of Visual Impairment in Wisconsin</u>

Visual impairment is among the disabilities Americans most fear<sup>5</sup>. Although half of all blindness can be prevented, the number of Americans who suffer from vision loss continues to increase. A study conducted by the Bureau for the Blind, Division of Disability and Elder Services, Department of Health and Family Services, in 2002 indicated that as many as 200,000 Wisconsin residents are severely visually impaired, of which approximately 118,000 are over the age of 55.

Age-related eye diseases are the leading causes of visual impairment and blindness in the United States. As those born in the post-war baby boom continue to age, the number of Americans affected by age-related eye diseases resulting in visual impairment is expected to triple by the year 2032<sup>6</sup>. The most common eye disorders affecting older Americans are cataracts, diabetic retinopathy, glaucoma, and age-related macular degeneration (AMD). Among those aged 55 and older in Wisconsin, the Bureau estimates that 394,000 individuals are affected by cataracts, 56,000 by diabetic retinopathy, 30,000 by glaucoma, and 33,000 by AMD<sup>7</sup>.

Fifty-two ophthalmologists, or 37 percent of those practicing in the state, responded to a survey developed in cooperation with the Wisconsin Academy of Ophthalmology. They reported serving clients in 59 counties throughout Wisconsin. The survey was designed to determine the number and demographic profile of patients receiving treatment for potentially blinding eye diseases. Based on the data obtained from this survey, Bureau estimates that in an average week in Wisconsin an ophthalmologist treats:

- 4 6 patients with diabetic retinopathy
- 5 7.5 patients with macular degeneration
- 10 14.7 patients with glaucoma

<sup>5,6</sup> Prevent Blindness America. 2002. Vision Problems in the U.S. Schaumburg, Illinois: 37 pp.

<sup>&</sup>lt;sup>7</sup> These estimates were calculated using 2000 U.S. Census data for Wisconsin and age-specific prevalence rates for each eye disorder calculated by Prevent Blindness America.

In addition, an ophthalmologist encounters one patient with optic atrophy every 5-8 weeks and one patient with retinal dystrophy every 10–14 weeks. Although less common than retinopathy, macular degeneration, or glaucoma, both optic atrophy and retinal dystrophy are potentially blinding.

When the above results are extrapolated to all ophthalmologists practicing in Wisconsin, they suggest that between 2,600-4,000 individuals with potentially blinding eye diseases are examined in the state every week. However, these data were gathered from physicians who worked in private practice or HMOs, mostly in urban areas. The majority of their clients were Caucasian. National research indicates that individuals in low income, minority, and/or rural populations are less likely to have knowledge of or access to vision health care, particularly if they are older<sup>8</sup>. Therefore, it is safe to assume that the figures in this survey underreport the true incidence of these disorders in Wisconsin.

#### **Health Concerns Associated with Visual Impairment**

Individuals experiencing vision loss often face restrictions in both mobility and activities of daily living. Half of all visually impaired individuals age 45 and older report that visual impairment interferes to some degree with activities in their daily lives<sup>9</sup>. Older people who are visually impaired are two times as likely to report having difficulty walking than their sighted age counterparts. They are also twice as likely to have difficulty getting into or out of beds or chairs than are sighted people. In addition, these individuals are more than three times as likely to report difficulties traveling outdoors or preparing meals<sup>10</sup>.

Research suggests that 18 percent of hip fractures are the result of impaired vision. The average cost of medical treatment for an individual with a hip fracture is \$35,000. It is estimated that the national cost of hip fractures related to visual impairment is more than \$2.2 billion per year<sup>11</sup>. If increased vision rehabilitation services could prevent only 20 percent of these injuries, the potential savings nationwide would be \$441 million per year. It is important to recognize that estimates of the cost of hip fractures attributed to visual impairment do not take into account the expense to the taxpayer of assisted living services, nursing homes,

<sup>&</sup>lt;sup>8</sup> Orr, A., 2000.

<sup>&</sup>lt;sup>9,11</sup> Leonard, R., 1999.

<sup>&</sup>lt;sup>10</sup> Crews, J., 2000.

or death. Therefore, these estimates are almost certainly far lower than actual long-term costs to both individuals and taxpayers.

From a broader perspective, visual impairment can have secondary health consequences that are not immediately apparent. For example, an individual who lacks mobility is not only restricted in travel, but is also deprived of the health benefits associated with regular exercise. In addition, difficulties in preparing healthy meals, often experienced by individuals with visual impairments, can result in a number of nutritionally related secondary medical conditions.

The extent of secondary health consequences resulting from visual impairment is not entirely understood. However, research indicates that when comparing visually impaired individuals to age mates with normal vision, those with visual impairments are <sup>12</sup>:

- 1.2 times as likely to experience arthritis or rheumatism
- 1.6 times as likely to experience hypertension
- 2 times as likely to experience cardiovascular disease
- 2.6 times as likely to have a stroke
- At increased risk for imbalance, falls, and hip fractures, making it more likely that they will be admitted to a hospital or nursing home, be disabled, or die prematurely <sup>13</sup>
- Less likely to report their health as excellent or very good and more likely to report their health as poor <sup>14</sup>
- 2.2 times more likely to report recurrent depression and anxiety. These affective responses to vision loss are largely attributable to diminished capacity to engage in routine activities such as driving and watching TV, limitations in opportunities to socialize, and fear that they will lose the ability to live independently in their own homes 15, 16

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<sup>&</sup>lt;sup>12</sup> Crews, J. 2000.

<sup>13</sup> http://www.aoa.dhhs.gov/naic/

<sup>&</sup>lt;sup>14,16</sup> Crews, J. and V.Campbell. 2001. *Health Conditions, Activity Limitations, and Participation Restrictions Among Older People with Visual Impairments*. Journal of Visual Impairment and Blindness 95: 453-467.

<sup>&</sup>lt;sup>15</sup> Orr. A. 2000

#### **Bureau for the Blind Clients and Services**

The Bureau staff of 14 Rehabilitation Specialists serves blind and visually impaired adults across all 72 counties in Wisconsin. Staff members provide services in one-to-one and group settings, creating specialized rehabilitation programs that are socially and culturally responsive to the context of an individual's community. In addition to teaching adaptive techniques to their clients, Specialists provide counseling, referrals, assistive devices and sustained support as they adjust to continued changes their visual impairment. The goal of Bureau programs is to enable people to maintain independence in their homes, places of employment, and communities. Services are provided free of charge.

Because the Bureau for the Blind recognized a lack of referrals from minority groups, a partnership was established with the Great Lakes Tribal Council to identify and serve individuals from all eleven Wisconsin Reservations. The Bureau also established a partnership with the Interfaith Older Adult Program in Milwaukee in order to serve Milwaukee County more widely.

#### **Cost Effectiveness**

Over a recent period of 12 months, the Bureau for the Blind served approximately 2,100 Wisconsin residents who are blind or visually impaired. The field personnel of the Bureau for the Blind teach their consumers how to remain healthy and safe while living independently. The average consumer receives 10 hours of direct service and adaptive equipment at an average cost of \$125. This means that for approximately \$675, older visually impaired people labeled "at risk" will live more independently, thus avoiding the cost of additional assisted living programs. Compared to nursing home or assistive living care, the cost of these Bureau services that enable seniors to remain in their homes with relative independence is both nominal and extremely cost effective to Wisconsin taxpayers.

#### **Profiles**

Below are profiles of clients who have achieved greater independence and life satisfaction through their use of Bureau for the Blind services.

#### Mrs. D., 85-year-old widow, Door County

Mrs. D. has been diagnosed with macular degeneration and glaucoma. When a Bureau for the Blind Rehabilitation Specialist first saw her, she was anxious about

losing her independence because her vision loss was preventing her from reading and signing her name or managing her monthly bills. She did not feel safe operating her stove or microwave, had difficulty pouring and measuring liquids while cooking, and had difficulty telling time, dialing her phone, and moving safely about her apartment.

Over a nine-month period, the client was served through a series of eight professional sessions. She was taught adaptive techniques, received adjustment counseling, and was provided with adaptive equipment. The total cost of this equipment was \$218, of which the Door County Office on Aging paid \$142. The client is now able to use her kitchen appliances safely through tactile identification, thus enabling her to prepare her own meals. She uses adaptive writing aids, such as signature guides and an enlarged check register to manage her own business affairs independently. She has also learned how to dial her telephone and use talking clocks. In addition, she has become an active participant in the talking books program. Because of the services she received from the Bureau, Mrs. D. has a more positive outlook on life and has greatly diminished her need for assistance from her family or community.

#### Ms. S., 33 years old, Milwaukee County

Ms. S. is severely visually impaired and has had to learn how to perform many activities of daily living. She reported that her most important concern was learning how to manage her money. She had been relying on her 11-year-old daughter to write checks and had to trust others to assist. With the help of Bureau services, she was taught how to organize bills and coins in her wallet so they could be identified by touch. She was also taught adaptive techniques for writing checks using a check-writing guide and trained to make a grocery list. These measures enable her to shop independently. She has also learned sighted guide techniques and been scheduled with Transit Plus to learn to travel independently within the community. This client has achieved a high degree of success in adapting to vision loss. She is highly motivated, and she is continuing to receive mobility training and additional rehabilitation services through the Division of Vocational Rehabilitation, Department of Workforce Development.

#### Mr. F., 75 years old, Oneida County

Mr. F. is legally blind as the result of diabetic retinopathy and macular degeneration. When first seen by the Rehabilitation Specialist, he expressed a high degree of frustration relative to his inability to perform many basic independent living tasks such as writing checks, identifying money, reading books, shaving, and

pouring liquids. Adding to his frustration was the fact that he was highly dependent on his wife to meet these daily living needs,

Over a seven-month period, Mr. F. received eight teaching sessions in which he learned to write checks with a signature guide, pour liquids using a level indicator, and shave using a magnifying mirror. He was also shown how to identify and organize money, and use a hand-held magnifier to read labels, menus, and signs. He is now able to enjoy the use of talking books and magazines. In addition, he received adjustment counseling to significantly diminish his frustration. The total cost of Mr. F.'s equipment was \$150 and the client shared part of this expense.

By the time Mr. F.'s case was closed, most of his frustration and dependence on his wife was gone. Additionally, he was reading independently, writing his own checks, and confident about writing notes and shaving himself.

#### Mrs. B., 76 year-old, Sheboygan County

"I am writing to let you know the tremendous difference the services and resources from the Bureau for the Blind have made in my life. The onset of my gradual vision loss began approximately ten years ago, when I was diagnosed with macular edema and glaucoma. I lost the vision in my left eye and all that remained was a narrow range of vision in the other eye. I was no longer able to drive and found that mobility and safety were of great concern. I lost much of my independence and the social life I had come to enjoy. My lack of depth perception resulted in several falls as I attempted to negotiate around the neighborhood. I had difficulty navigating stairs and clearing corners. I found myself afraid to venture from the familiarity of my apartment and dependent on family members for simple things like shopping and going to church. The future was a frightening proposition. Around that time, a friend told me about the support provided by the Wisconsin Bureau for the Blind, and I began to receive their services.

Since that time, I have attended several workshops conducted by members of the Bureau's staff. I learned a number of strategies that have enabled me to handle my finances, increase my mobility, and provide for my daily needs. The Bureau sent a trained professional to my home to evaluate how to adapt my environment for safety and function and encouraged my family to accompany me to workshops, which enhanced their understanding of what I was going through and needed to do to decrease my dependence on them. I was also put in touch with a network of supportive services and agencies...and have had many opportunities to meet with other individuals who are coping with vision loss.

Because of the support of the Wisconsin Bureau for the Blind, I am able to lead my life with dignity and relative independence. In these times of limited state resources, I am hoping our government officials are wise enough to realize that agencies such as the Bureau for the Blind are cost effective because they keep individuals like me functioning and independent. Thank you for all you have done and your continued support."

#### **Consumer Satisfaction with Bureau for the Blind**

The Bureau for the Blind (Bureau) conducts annual consumer surveys to obtain feedback from clients relative to their level of satisfaction and the benefits they received from Bureau services. Of those participating in the last Consumer Survey, completed during January-June 2001:

- 81 percent reported increased self-confidence and independence
- 80 percent improved their ability to read
- Nearly 70 percent indicated that they were more in control of important life decisions
- 68 percent were better able to socialize and participate in activities with their family, friends, and community
- About two-thirds were better able to manage their paperwork tasks
- More than half had increased their mobility (57 percent), ability to prepare meals (57 percent), or ability to manage their housekeeping tasks (55 percent)

Many people indicated that the program had improved their quality of life. Most all respondents increased their levels of independence. Younger respondents indicated that the program had increased their mobility, ability to prepare meals and read, while older respondents were more likely to perform housekeeping duties again and regain their ability to socialize. Both age groups were equally likely to have experienced positive results in their ability to handle paperwork, make decisions, and participate in social interactions.

Below are some of the comments made by survey respondents regarding the difference Bureau programs have made in their lives:

"It gave me the hope that I may be able to live in my house and care for myself. God bless you for the help you gave me!"

-- 83-year-old Marinette County resident

"This program makes me feel I am not alone and thankful for the help I can get."

- -- 79-year-old Dane County resident
- "...thank you so very much for your help. You are very good at what you do...as we all struggled and floundered with the impairment, your thoughtfulness and kindness will always be remembered"
  - --A.V.B. family

"The fact that I now have a central place to go for assistance when the need arises is a great relief to me."

-- 87-year-old Milwaukee County resident

"I feel more independent and am more comfortable about asking for help."

-- 78-year-old Kewaunee County resident

"I recommend you highly to friends. You helped me a lot. Keep up the good work."

--Ms. F.M.

"The use of the talking library and talking books has opened up a new world of learning and entertainment for me. I truly treasure this wonderful privilege. Thank you, thank you! I tell everyone about this."

-- Eau Claire County resident

"This program has given me back my independence. I can do again...what I could not do before."

-- 89-year-old Waukesha County resident

"This program has given me hope. I know that there is an organization that can help me. That is important."

-- 76-year-old Milwaukee County resident

#### **Summary**

The Bureau for the Blind, Division of Disability and Elder Services, Department of Health and Family Services is dedicated to providing quality services to adults who are blind and/or visually impaired. Bureau services keep the vulnerable older population experiencing vision loss healthy and safe while maintaining their independence. The Bureau also assists the visually impaired population returning to work by identifying reasonable accommodations and providing adaptive training. When surveyed, the majority of consumers credited Bureau services with increasing their quality of life.

When consumers remain in their homes, the extraordinary cost of assisted living services or institutionalization is avoided, which results in long term cost savings. By returning individuals back to the workforce, it increases the tax base and decreases state subsidies.

The challenge for the future is providing quality services for a rapidly increasing older population, experiencing vision loss, with decreasing resources.

-- Michael Nelipovich, RhD., Director of the Bureau for the Blind

#### For more information, please call: Bureau for the Blind Toll-free 1-888-879-0017

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